

SOUTH AUSTRALIAN TASK FORCE ON MULTIPLE CHEMICAL SENSITIVITY

Submission No 444

Responding To The Environmental Public Health Crisis Of Chemical Injury

• Postal Address: PO Box 3308 Port Adelaide 5015 • Telephone (08) 8240 5084 • Email: satfmcs@optusnet.com.au

Submission to the
House Standing Committee on Legal and Constitutional Affairs

Regarding the Draft
Disability (Access to Premises - Buildings) Standards

By
Peter Evans, RN (formerly), Grad Dip Soc. Sc.
Convenor
SA Task Force on MCS

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ABOUT THE AUTHOR

Peter Evans is a former registered nurse and health counsellor who began experiencing symptoms of multiple chemical sensitivity (MCS) in 1984 following exposure to phenolic disinfectants and formaldehyde in the health care setting. He was diagnosed with chronic fatigue syndrome in 1990. In 1994 his chronic symptoms and associated disability were acutely exacerbated by sick building syndrome while working in a newly constructed, tightly sealed building. Following a period of disabling illness requiring total chemical avoidance, he recovered sufficiently to return to working life. But in 2000, after being exposed to a combination of organophosphate pesticides used in the South Australian government's suburban fruit fly eradication program, he became too chemically sensitive and permanently disabled to engage in paid employment. Subsequently his illness and associated disability further declined following sensitisation and severe reactivity to herbicides used in local government weed control programs. Peter has a significant family history of MCS with all of his adult siblings disabled with the condition. In 2001 he became involved in the community response to MCS and established the SA Task Force on MCS. He was medically diagnosed with MCS in 2004. Peter is a community representative with the interagency MCS Reference Group convened by the SA Dept of Health.

ABOUT THE SA TASK FORCE ON MCS

The South Australian Task Force on Multiple Chemical Sensitivity is a community-based group of people living with MCS. Our aims are 1) to raise awareness of the serious public health and disability access problems associated with many common chemicals, often at levels assessed by regulatory authorities as acceptable for the general population and 2) to promote institutional, community and workplace policy changes that will help to end the widespread discrimination facing people with MCS.

SATFMCS uses a community activist model as a basis for its work. This involves conducting public rallies and public meetings, lobbying governments, political representatives and bureaucrats, collaborating with disability advocates, raising community awareness of MCS, and encouraging community-based organisations to include MCS in their disability access plans and occupational health and safety policies.

Following persistent lobbying by SATFMCS, a Parliamentary Inquiry into MCS in SA was conducted by the Social Development Committee, with the findings tabled in the Legislative Council in 2005. The Inquiry concluded that “MCS is very real and that many individuals experience considerable suffering, particularly in light of the lack of recognition surrounding this condition”. The inquiry resulted in a number of ground breaking recommendations including that: “the [Department of Health] collaborates with the Department for Families and Communities (DFC) and other appropriate agencies and organisations, with the view to exploring practical measures that could assist in addressing disability access issues experienced by MCS sufferers, in relation to public facilities and services in the community.”

A full copy of the Inquiry into MCS report is available at:

<http://www.parliament.sa.gov.au/Committees/Standing/LC/SocialDevelopmentCommittee/CompletedInquiries/22NdReportMultipleChemicalSensitivity.htm>

WHAT IS MCS?

Descriptions of hypersensitivity reactions to low level chemical exposures have existed in the medical literature since the 1950s when the condition was referred to as “the petrochemical problem”. Currently there is no fully accepted definition of MCS, although the term was first proposed in 1987 by Cullen to describe unusual hypersensitivity reactions to low levels of environmental exposures. In 1999, based on internationally agreed criteria, Bartha et al. defined it as a chronic condition with multiple symptoms, occurring reproducibly in multiple organ systems, in response to low-level exposure to multiple unrelated chemicals (often at levels previously or commonly tolerated), which improve or resolve when the incitants are removed (Bartha, et al., 1999). In 2005 Lacour et al., proposed that this definition be extended to include exposure-related non-specific complaints of the central nervous system.

There is no single diagnostic test for MCS and no known cure. The condition is frequently associated with severe disability. Symptoms often follow a chronic relapsing picture, although after the initial onset some people may recover sufficient levels of health to return to relatively normal function. However, they usually continue to experience disabling symptoms and remain vulnerable to chemical exposures and relapse in the vast majority of cases. The most effective treatments for MCS are chemical avoidance, maintaining a chemical-free living space, prayer and meditation (Reed Gibson, 2003).

It has been proposed by researchers studying the phenomenon that MCS develops in two phases. The first phase, initiation, occurs following exposure to a reportedly wide range of chemicals. International research across several continents has consistently identified pesticides, petrochemicals, organic solvents, and sterilising agents as some of the most common initiating agents in MCS. Following initiation, sensitivities then broaden to include multiple unrelated chemicals found commonly in everyday products like perfumes, cleaning agents, building and renovating materials, tobacco smoke, vehicle exhaust, pesticides, new carpets and furnishings, and many others (Ashford and Miller, 1998; Caress and Steinemann, 2003).

It has been observed that, following the early initiation of symptoms of MCS, some people may not go on to develop chronic illness provided that they follow timely advice to avoid those chemical agents associated with the onset of symptoms. This suggests that MCS is a preventable condition and European researchers have recommended the development of a comprehensive public health strategy to prevent MCS (Ashford and Miller 1998).

Common symptoms of MCS include:

- Difficulty concentrating
- Fatigue
- Nasal congestion
- Forgetfulness/poor memory
- Irritability

- Headache
- Itchy eyes
- Trouble finding the right words
- Need to clear throat
- Difficulty making decisions
- Stuffy or full sinuses
- Muscle/joint pain and stiffness
- Feeling light-headed (Joffres, M., et al., 2001)

There is significant overlap between multiple chemical sensitivity and other emerging public health problems such as chronic fatigue syndrome and fibromyalgia (Ashford and Miller 1998). However, Lacour et al., (2005) list over forty disease states, including HIV, heart disease, lung disease, and diabetes, which may overlap with MCS-defining symptoms.

An overview of the health hazards associated with common chemical exposures is attached to this submission (Steinemann, 2005a, 2005b).

HOW MANY PEOPLE HAVE MCS?

A Department of Health study in NSW in 2002 found that 2.9% of respondents have been medically diagnosed with chemical sensitivity, with 24.6% reporting sensitivity to chemical odours. Similar Department of Health studies in SA in 2002 and 2004 found that 0.9% of respondents have been medically diagnosed with MCS, with 16.4% reporting sensitivity or health effects from chemical exposures. The SA Inquiry into MCS concluded that “Interstate and overseas research has shown that up to 6 percent of the population may have MCS, with between 10-25 percent experiencing sensitivity to chemicals”. Medical evidence to the Inquiry suggested that the incidence of MCS is increasing in the community (Parliament of SA, 2005).

These data indicate that the number of people affected by MCS is large and that the adverse impacts and associated costs of MCS in the community are extensive. There is most likely a continuum of illness severity within the estimated 6% of the population with MCS, with perhaps 1-2% being severely disabled.

Published data on the incidence of MCS, together with common environmental symptom triggers in MCS, from the SA Department of Health is attached to this submission (Fitzgerald, 2008).

INDOOR AIR POLLUTION – A DISABILITY ACCESS BARRIER

Changes in building design since the oil crisis of the 1970s have resulted in closed buildings that are tightly sealed without windows that open and are air-conditioned with limited fresh air exchange in order to minimise heating and cooling costs. Since that time sick building syndrome caused by volatile organic compounds in indoor air has been an increasingly common phenomenon that is also associated with MCS (Silberschmidt, 2005; Ashford and Miller, 1998).

The emergence of MCS and environmental sensitivities generally has resulted in serious disability access problems in the built environment. Consequently people with MCS are often unable to access indoor spaces and associated services without experiencing severe and disabling symptoms due to exposure to chemicals in indoor air. Exposure to volatile organic compounds in indoor air is typically 5 to 50 times higher than outdoors, even in heavily polluted cities (Steinemann, 2005a). This problem not only applies to newly constructed buildings but also to those that have been recently renovated and those that bring toxic materials into the enclosed environment.

The Australian Human Rights Commission (AHRC) recognises MCS and other environmental sensitivities such as fragrance sensitivity as disabilities under the *Disability Discrimination Act*. Consequently, reasonable accommodation must be made for people with these disabling health conditions. Related AHRC guidelines on chemical sensitivity are available at http://www.hreoc.gov.au/disability_rights/buildings/guidelines.htm and state:

Use of chemicals and materials

A growing number of people report being affected by sensitivity to chemicals used in the building, maintenance and operation of premises. This can mean that premises are effectively inaccessible to people with chemical sensitivity. People who own, lease, operate and manage premises should consider the following issues to eliminate or minimise chemical sensitivity reactions in users: the selection of building, cleaning and maintenance chemicals and materials (see Note below); the provision of adequate ventilation and ensuring all fresh air intakes are clear of possible sources of pollution such as exhaust fumes from garages; minimising use of air fresheners and pesticides; the provision of early notification of events such as painting, pesticide applications or carpet shampooing by way of signs, memos or e-mail.

For more information on ways to eliminate or minimise chemical and fragrance sensitivity reactions look at <http://www.jan.wvu.edu/media/MCS.html> and <http://www.jan.wvu.edu/media/fragrance.html>

Note: There are a number of relevant environmental and occupational health and safety regulations and established standards, however, as is currently the case with other standards referenced in building law, compliance with those standards may not necessarily ensure compliance with the DDA.

Unfortunately, general ignorance and denial of the problem, coupled with a history of indifference to MCS policy development by Australian governments at all levels, has meant that people with MCS are frequently denied their basic human rights. This lack of MCS policy development is reflected in the fact that the above AHRC guidelines actually refer to US documents from their Job Accommodation Network. No comprehensive Australian MCS guidelines exist and there is considerable lethargy with the respect to the development of disability access provisions for people with environmental sensitivities. Senior policy staff at AHRC have advised the community-based Australian MCS Network that:

Submissions in relation to MCS have been made on numerous occasions by organisations representing people with multiple chemical sensitivity.

The draft Premises Standards at this stage is limited to addressing those access related issues covered by the current Building Code of Australia (BCA). As the BCA does not currently address issues such as chemical sensitivity the Premises Standards also does not cover them. This is also the case for other areas of access such as fitout and wayfinding for blind people. It may be that in the future these issues will be considered further.

This situation is totally unacceptable to people with MCS and environmental sensitivities and potentially has significant legal implications.

The Commonwealth Office of Chemical Safety and the National Industrial Chemicals Notification and Assessment Scheme are currently conducting a scientific review of MCS. A draft of the document for public comment is available at [http://www.health.gov.au/internet/main/publishing.nsf/Content/63D8BC270AC92502CA2574F8001BCDF9/\\$File/MCSdrafReport.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/63D8BC270AC92502CA2574F8001BCDF9/$File/MCSdrafReport.pdf). Unfortunately this review has not considered disability access or other sociological aspects of MCS and has overemphasised unproven psychological causes for MCS, despite good evidence that it is a physiological condition with predetermining genetic factors. This aetiological debate has greatly hampered any precautionary progress on MCS. However, with regard to the provisions of the *Disability Discrimination Act*, reasonable accommodation must be made for people with MCS regardless of the aetiology of the condition.

Formal government recognition of MCS and other environmental sensitivities, coupled with the development of building standards that assist people disabled with these conditions to access the built environment, are urgently needed to address this growing problem. The development of green building standards has assisted to some degree but these standards are not always consistent with MCS disability access and more specific work needs to be done.

In 2007 the Canadian Human Rights Commission published a report into the legal perspective of disability access for people with environmental sensitivities. The document, which is attached to this submission, recommends that:

When reviewing their building codes, governments across Canada proactively address issues related to accommodation of people with disabilities, especially disabilities that are difficult to address retrospectively, such as environmental sensitivities. (Wilkie and Baker, 2007).

The Danish Inquiry into MCS, with recommendations for improved MCS prevention and disability access strategies, is attached (Silberschmidt, 2005).

A report from a 1995 workshop of the American Thoracic Society on how to improve indoor air quality, including problem solving in building design, construction and operation, is attached (ATS Workshop Report, 1997).

There is no reason why Australia should neglect its public health and disability access responsibilities in this matter. Strategies that provide improved MCS disability access will also help to prevent MCS.

INTERNATIONAL RECOGNITION OF MCS DISABILITY ACCESS TO BUILDINGS

Australia is decades behind the USA and Canada with regard to its disability access policy response to MCS and other environmental sensitivities.

In 2005 the USA's National Institute of Building Sciences (NIBS) published comprehensive guidelines for MCS disability access to buildings. Entitled IEQ Indoor Environmental Quality, the document is attached to this submission and states:

Many new building materials, such as paints, adhesives, wallboard, carpet, and insulation, as well as upholstered furniture, particleboard cabinets, and other furnishings emit hazardous volatile organic compounds (VOC's), contribute to poor indoor air quality (IAQ) and create significant access barriers for people with asthma and/or chemical sensitivities. These materials often outgas and are problematic for prolonged periods of time.

With regard to building design the document states:

The Products & Materials Committee believes that particular attention is critical during building design to assure that the needs of chemically and electromagnetically sensitive people are accommodated to the greatest extent possible. In general, this means selection of construction materials that are low-emitting or non-emitting and selection of finishes that do not absorb or react with chemicals emitted by other materials or products in the building. To begin to address some of the concerns of electromagnetically sensitive persons, areas of the building can be designed to have reduced electromagnetic fields. By making indoor environments that are safer for the most vulnerable among us, we can create indoor environments that are healthier for everyone, especially children.

Generally, this means selection of materials that are "hard" or non-porous where possible so that any chemicals that contact these materials are not retained in and re-emitted from them. Also, particular attention should be paid to selection of materials that will not require VOC-emitting chemicals later as part of maintenance. For instance, in designing building foundations and structures, particular attention should be

paid to the need for preventing termite problems, since the pesticides commonly used to control termites can have a deleterious effect on humans, especially persons with multiple chemical sensitivities. So, even though the material itself might be low-emitting, the use of products meant to "preserve, protect, or maintain" the material selected might emit volatile fumes that degrade indoor environmental quality and result in a building that is not suitable for persons with MCS.

The NIBS guidelines also contain comments on the selection of low chemical emission building materials.

The House Standing Committee's comprehension of MCS disability access issues would be greatly enhanced by a close perusal of this document. Some reference to the NIBS Indoor Environment Quality guidelines in the final Disability (Access to Premises – Buildings) Standards would be a very welcome inclusion to assist the disability access needs of people with environmental sensitivities.

The US state of California has independently developed environmental sensitivity disability access standards to buildings. A public information brochure on this development entitled Cleaner Air is attached to this submission.

INDOOR AIR POLLUTION IN AUSTRALIA

In 2000 the Department of the Environment and Heritage published its State of Knowledge Report: Air Toxics and Indoor Air Quality in Australia. The document, which is attached to this submission, identifies numerous chemicals of concern in indoor air that are associated with MCS.

Chapter B 3.4 entitled Reduction of Indoor Sources states:

Many indoor air pollutants have clearly identifiable sources. It is now widely accepted overseas that controlling emissions is the most important strategy for achieving improved indoor air quality. In Australia, Brown et al. (1992), Gilbert (1993) and NH&MRC (1993) have recommended this approach.

ANZECC (1990) found a need for concerted and coordinated action by all levels of government and associated bodies to ensure that air quality in Australian indoor environments is improved in a planned and cost-effective manner.

The document highlights the need for low formaldehyde emitting pressed wood materials. It also notes that Immig et al (1997) have outlined selection criteria for an extensive range of building and furnishing materials to limit sources of indoor air pollutants, including general criteria, and specific criteria for surface finishes, sealants, adhesives, insulation, plywood and wood panels, floor coverings, furniture and appliances.

Unfortunately since the publication of the State of Knowledge Report insufficient action has been taken to properly address poor indoor air quality in Australia. There is currently no single federal agency responsible for indoor air pollution issues and no over-arching national strategy to improve and maintain indoor air quality.

CONCLUSION

A national policy failure in the development in MCS disability access guidelines coupled with unaddressed indoor air pollution problems has resulted in considerable public health and disability access impacts. The current draft Disability (Access to Premises – Buildings) Standards before the House Standing Committee therefore presents an opportunity for the Australian government to address this problem by including provisions for MCS associated disability access in the proposed legislation. If the sources of indoor air

pollution are “clearly identifiable”, as noted in the Department of the Environment and Heritage State of Knowledge Report, then they should be removed wherever possible from the built environment.

RECOMMENDATIONS

The draft Disability (Access to Premises – Buildings) Standards have been in development for a number of years. During that time there has been no consideration given to the disability access needs of people with MCS or environmental sensitivities. There is currently no reference to the problem of chemical sensitivity in the draft document. Hopefully this omission will be addressed by the House Standing Committee.

However, given the ongoing lethargy and general denial surrounding MCS in Australia, it would appear unlikely that comprehensive disability access guidelines in MCS related buildings standards will be developed for the Disability (Access to Premises – Buildings) Standards at this stage. However, some kind of reference in the Standards to the need to reduce indoor air pollution through careful product selection and methods of construction and maintenance, perhaps as a voluntary measure, would be consistent with the spirit of providing equitable disability access to people with MCS and other environmental sensitivities. Certainly reference to the US National Institute of Building Sciences IEQ Indoor Environmental Quality guidelines would be a welcome addendum.

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